



Date as postmark

Dear [participant](#)

Re: Invitation to participate in a research project.

The purpose of this letter is to invite you to participate in a research study. The participant information sheet enclosed provides details of the purpose of the study, which you need to consider before deciding whether you would be willing to take part.

You are not obliged to take part in this study. If you do agree to participate, you remain free to withdraw from the study at any time and may do so without any disadvantage to yourself and without any obligation to give a reason.

If you decide that you would like to participate in the study once you have considered the information provided, please complete and complete the forms electronically and email them back to me by 3rd December 2010

Please do not hesitate to contact me if you would like to discuss the information provided or ask any questions before agreeing to part in the study.

Many thanks for taking the time to read this information.

Yours sincerely

Leonore Lord

Chronic Illness Research Team

Telephone: 07957395575

Email: u0925703@uel.ac.uk



Participant Information Sheet

**University of East London
Stratford Campus
Water Lane
London, E15 4LZ**

University Research Ethics Committee

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact the Secretary of the University Research Ethics Committee: Ms S Thorne, Administrative Officer for Research, Graduate School, University of East London, Romford Road, Stratford, E15 4LZ. Telephone: 0208 223 6274. Email: s.r.c.thorne@uel.ac.uk

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Consent to participate in a research study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project title

An investigation of the way psychosocial factors and illness variables affect depression within people with Multiple Sclerosis (MS).

Project description

Recent studies have also indicated that people with MS tend to be concerned about their role limitations, social status, emotional aspects as well as the physical disability noting that quality of life can worsen even before physical disability become an evident problem.

An important goal of researchers is improving the quality of life of people with chronic illnesses by gaining an understanding of the behavioural, psychological and social variables that effect quality of life and impact on depression.

This project will focus on three psychosocial variables stigma, fatigue and uncertainty investigating how they impact on people with MS.

I do have a confirmed diagnosis of MS, so why are you inviting me to participate in this study?

The aim of this exploratory study is to identify how with people with a diagnosis of Clinical MS, Probable MS or CIS (Clinical isolate Syndrome) are affected by their diagnosis. The progression and symptoms of MS and many other hidden conditions are unpredictable yet are known to have a massive impact of a person's quality of life the severity of the symptoms are not a reliable indicator of the degree that the diagnosis affects the quality of life os a person.

In the long-term, such information could lead to a better understanding of the impact of a chronic illness and the range of problems experienced by people with a chronic illness like MS, the potential underlying causes of depression and the type's interventions that could help to improve their quality of life.

If I agree to participate, what will I be required to do?

If you do decide to participate, you will be asked to complete six brief questionnaires, which require you to indicate the extent to which you agree or disagree with a series of statements using a rating scale and circling the answer that best describes your situation. The questionnaire is design to measure how your MS impact on you and your quality of life and also a pre assessment questionnaire and return a consent form by email to u0925703@uel.ac.uk or lordleonore@hotmail.com.

They should take no longer than 30 minutes to complete in total you may complete them in any order.

Many participants enjoy taking part in such studies, as well as gaining personal satisfaction from contributing important information to research at the University of East London.

Will the task pose any risks to me?

None this is written task. If you are uncomfortable answering any questions you are advised to leave it blank

Confidentiality of the data

The information obtained as part of this project will be treated in confidence and will not be made available to anyone else. All of the data that you provide will be coded to safeguard your anonymity. All data will be stored securely and accessed solely by the research team. Once the project has been completed, all data collected will be destroyed. You are free to ask for your data to be withdrawn from the study and to be destroyed at any time.

Location

This is a email questionnaire

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time during the tasks. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without obligation to give a reason.

University of East London

Consent to Participate in a Research Study

Project title: *An investigation of the way psychosocial factors and illness variables affect depression within people with Multiple Sclerosis (MS).*

I have read the participant information sheet relating to the above research study in which I have been asked to participate and have been given a copy for my own records. The nature and purpose of the research has been explained to me, and I have been given the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the nature of the procedures in which I will be involved.

I understand that my involvement in this study and any data that I provide will remain strictly confidential. Only the researchers involved in the study will have access to the data, which will be coded to ensure anonymity. It has been explained to me what will happen to the data once the research study has been completed.

I hereby fully and freely consent to participate in the study, which has been fully explained to me.

Having given this consent, I understand that I retain the right to withdraw from the research study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's name (BLOCK CAPITALS):.....

Participant's signature:.....Date:.....

Researcher's name: Leonore Lord

Researcher's signature:.....Date:....18th November 2010.....

University of East London
Pre-Assessment Questionnaire

Project title: *An investigation of the way psychosocial factors and illness variables affect depression within people with Multiple Sclerosis (MS).*

The purpose of this questionnaire is to gather some initial background data and to ensure that it is appropriate for you to take part in the above study. Details of the study have been enclosed with this questionnaire for your consideration.

Age.	
Gender (please circle).	Male / Female
Are you currently taking any prescribed medication?	Yes / No
If you answered "yes" to the above question, please state the name of the medication that you are taking.	
Have you been diagnosed by a medical professional with any form of long-term psychological or physical illness?	Yes/No
If you answered "yes" to the above question, please state the long-term psychological or physical illness. and some of your symptoms	

Section 1
MFI MULTIDIMENSIONAL FATIGUE INVENTORY
E. Smets, B.Garssen, B. Bonke.

Instructions:

By means of the following statements we would like to get an idea of how you have been feeling **lately**.

There is, for example, the statement: "I FEEL RELAXED"

If you think that this is **entirely true**, that indeed you have been feeling relaxed lately, please, place an **X** in the extreme left box; like this:

yes, that is true _1 _2 _3 _4 **x5** **no, that is not true**

The more you **disagree** with the statement, the more you can place an **X** in the direction of "no, that is not true". Please do not miss out a statement and place only one **X** in a box for each statement.

- | | | | | | | | |
|--|-------------------|----|----|----|----|----|----------------------|
| 1 I feel fit. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 2 Physically, I feel only able to do a little. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 3 I feel very active. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 4 I feel like doing all sorts of nice things. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 5 I feel tired. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 6 I think I do a lot in a day. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 7 When I am doing something, I can keep my thoughts on it. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 8 Physically I can take on a lot. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 9 I dread having to do things. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 10 I think I do very little in a day. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 11 I can concentrate well. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 12 I am rested. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 13 It takes a lot of effort to concentrate on things. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 14 Physically I feel I am in a bad condition. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 15 I have a lot of plans. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 16 I tire easily. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 17 I get little done. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 18 I don't feel like doing anything. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 19 My thoughts easily wander. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |
| 20 Physically I feel I am in an excellent condition. | yes, that is true | _1 | _2 | _3 | _4 | _5 | no, that is not true |

Section2

HADS

This questionnaire is designed to help us know how you feel. Read each item and mark with a **x** the reply which comes closest to how you have been feeling in the past week. Do not take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. **I feel tense or 'wound up':**
 - Most of the time
 - A lot of the time
 - From time to time, occasionally
 - Not at all
2. **I still enjoy the things I used to enjoy:**
 - Definitely as much
 - Not quite so much
 - Only a little
 - Hardly at all
3. **I get a sort of frightened feeling as if something awful is about to happen:**
 - Very definitely and quite badly
 - Yes, but not too badly
 - A little, but it doesn't worry me
 - Not at all
4. **I can laugh and see the funny side of things:**
 - As much as I always could
 - Not quite so much now
 - Definitely not so much now
 - Not at all
5. **Worrying thoughts go through my mind:**
 - A great deal of the time
 - A lot of the time
 - From time to time but not too often
 - Only occasionally
6. **I feel cheerful:**
 - Not at all
 - Not often
 - Sometimes
 - Most of the time

7. **I can sit at ease and feel relaxed:**
Definitely
Usually
Not often
Not at all
8. **I feel as if I am slowed down:**
Nearly all the time
Very often
Sometimes
Not at all
9. **I get a sort of frightened feeling like 'butterflies' in the stomach:**
Not at all
Occasionally
Quite often
Very often
10. **I have lost interest in my appearance:**
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever
11. **I feel restless as if I have to be on the move:**
Very much indeed
Quite a lot
Not very much
Not at all
12. **I look forward with enjoyment to things:**
As much as ever I did
Rather less than I used to
Definitely less than I used to
Hardly at all
13. **I get sudden feelings of panic:**
Very often indeed
Quite often
Not very often
Not at all
14. **I can enjoy a good book or radio or TV programme:**
Often
Sometimes
Not often
Very seldom

Section3

The SSCI for neurological conditions

Please read the following items and rate how true the statement was for you.

		1	2	3	4	5
Item	Statement	Never	Rarely	Often	Sometimes	always
	<i>Lately:</i>					
1	Because of my illness, I felt emotionally distant from other people					
2	Because of my illness, I felt left out of things					
3	Because of my illness, I felt embarrassed in social situations					
4	Because of my illness, I worried about other people's attitudes towards me					
5	I was unhappy about how my illness affected my appearance					
6	Because of my illness, it was hard for me to stay neat and clean					
7	Because of my illness, I worried that I was a burden to others					
8	I felt embarrassed about my illness					
9	I felt embarrassed because of my physical limitations					
10	I felt embarrassed about my speech					
11	Because of my illness, I felt different from others					
12	I tended to blame myself for my problems					
13	I avoided making new friends to avoid telling others about my illness					
14	Because of my illness, some people seemed uncomfortable with me					
15	Because of my illness, some people avoided me					
16	Because of my illness, people were unkind to me					
17	Because of my illness, people made fun of me					
18	Because of my illness, people avoided looking at me					
19	Because of my illness, strangers tended to stare at me					
20	Because of my illness, I was treated unfairly by others					
21	Because of my illness, people tended to ignore my good points					
22	Some people acted as though it was my fault I have this illness					
23	People with my illness lost their jobs when their employers found out about it					
24	I lost friends by telling them that I have this illness					

Section 4

FEELINGS ABOUT MY ILLNESS

Below are 30 statements. Please read the statement and put a tick in the box, which most represents your feelings. 1 = strongly disagree; 2 = disagree; 3 = neither agree nor disagree; 4 = agree; 5 = strongly agree. Please do not think too long about the answers. If you are certain that a question does not apply to you (e.g. q18 may not apply if you are not under the care of a hospital) please tick the appropriate row under the "not applicable" (n/a) column.

		n/a	SD	D	N	A	SA
	Statement		1	2	3	4	5
1.	I don't know what is wrong with me						
2.	I have a lot of questions without answers						
3.	I am unsure if my illness is getting better or worse						
4.	It is unclear how bad my pain will be						
5.	The explanations they give seem hazy to me						
6.	The purpose of each treatment is clear to me						
7.	When I have pain I know what it means about my condition						
8.	I do not know when to expect things will be done to me						
9.	My symptoms continue to change unpredictably						
10.	I understand everything explained to me						
11.	The doctors say things to me that could have many meanings						
12.	I can predict how long my illness will last						
13.	My treatment is too complex to figure out						
14.	It is difficult to know if the treatments or medications I am getting are helping me						

15.	There are so many different types of staff, it's unclear who is responsible for what						
16.	Because of the unpredictability of my illness, I cannot plan for the future						
17.	The course of my illness keeps changing; I have my good and bad days						
18.	It's vague to me how I will manage after I leave the hospital						
19.	I have been given many differing opinions about what is wrong with me						
20.	It is not clear what is going to happen to me						
21.	I usually know if I am going to have a good or bad day						
22.	It is clear to me when I am getting better or worse						
23.	They have not told me how they will treat my illness						
24.	It is difficult to determine how long it will be before I can care for myself						
25.	I can generally predict the course of my illness						
26.	They give me so much information that I cannot tell what is most important						
27.	I feel sure that my physical strength will eventually return						
28.	The doctors share the same opinion about how to treat my problem						
29.	They have not given me a specific diagnosis						
30.	My physical distress is predictable; I know when it is going to get better or worse						

Section 5

PSS Questionnaire

Please respond to each of the following items separately by choosing one number for each. Make the answers as true to you as possible, using the responses listed below:

0 = Never

1 = Almost Never

2 = Sometimes

3 = Fairly often 4 = Very often

1. In the last month, how often have you been upset because of something that happened unexpectedly.
2. In the last month, how often have you felt that you were unable to control the important things in your life?
3. In the last month, how often have you felt nervous and stressed?
4. In the last month, how often have you dealt with irritating life hassles?
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?
6. In the last month, how often have you felt confident about your ability to handle your personal problems?
7. In the last month, how often have you felt that things were going your way?
8. In the last month, how often have you found that you could not cope with all the things that you do?
9. In the last month, how often have you been able to control irritations in your life?
10. In the last month, how often have you felt that you were on top of things?
11. In the last month, how often have you been angered because of things that happened that were outside of your control?
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?
13. In the last month, how often have you been able to control the way you spend your time?
14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

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Section 6

Multiple Sclerosis Impact Scale (MSIS-29)

The following questions ask for your views about the impact of MS on your day-to-day life **during the past two weeks**

For each statement, please **mark** the **one** number that **best** describes your situation Please answer **all** questions

In the <u>past two weeks</u> , how much has your MS limited your ability to...		Not at all	A little	Moderately	Quite a bit	Extremely
1.	Do physically demanding tasks?	1	2	3	4	5
2.	Grip things tightly (e.g. turning on taps)?	1	2	3	4	5
3.	Carry things?	1	2	3	4	5

In the <u>past two weeks</u> , how much have you been bothered by...		Not at all	A little	Moderately	Quite a bit	Extremely
4.	Problems with your balance?	1	2	3	4	5
5.	Difficulties moving about indoors?	1	2	3	4	5
6.	Being clumsy?	1	2	3	4	5
7.	Stiffness?	1	2	3	4	5
8.	Heavy arms and/or legs?	1	2	3	4	5
9.	Tremor of your arms or legs?	1	2	3	4	5
10.	Spasms in your limbs?	1	2	3	4	5
11.	Your body not doing what you want it to do?	1	2	3	4	5
12.	Having to depend on others to do things for you?	1	2	3	4	5

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In the <u>past two weeks</u>, how much have you been bothered by...		Not at all	A little	Moderately	Quite a bit	Extremely
13.	Limitations in your social and leisure activities at home?	1	2	3	4	5
14.	Being stuck at home more than you would like to be?	1	2	3	4	5
15.	Difficulties using your hands in everyday tasks?	1	2	3	4	5
16.	Having to cut down the amount of time you spent on work or other daily activities?	1	2	3	4	5
17.	Problems using transport (e.g. car, bus, train, taxi, etc.)?	1	2	3	4	5
18.	Taking longer to do things?	1	2	3	4	5
19.	Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?	1	2	3	4	5
20.	Needing to go to the toilet urgently?	1	2	3	4	5
21.	Feeling unwell?	1	2	3	4	5
22.	Problems sleeping?	1	2	3	4	5
23.	Feeling mentally fatigued?	1	2	3	4	5
24.	Worries related to your MS?	1	2	3	4	5
25.	Feeling anxious or tense?	1	2	3	4	5
26.	Feeling irritable, impatient, or short tempered?	1	2	3	4	5
27.	Problems concentrating?	1	2	3	4	5
28.	Lack of confidence?	1	2	3	4	5
29.	Feeling depressed?	1	2	3	4	5

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